



Medical sessions

4 July 2014 (Friday)	
8.00 a.m. - 9:00 a.m.	Registration
9.00 a.m. - 11.00 a.m.	Fundamental sciences for the development of knowledge about rare diseases
11.20 a.m. - 1.00 p.m.	New diagnostic methods in metabolic diseases
2.00 p.m. - 4.00 p.m.	New diagnostic methods in genetic disorders
4.20 p.m. - 6.00 p.m.	Pathophysiology and clinical manifestations of selected metabolic diseases
7:00 p.m.	Barbecue (Dinner)
5 July 2014 (Saturday)	
8.00 a.m. - 10.00 a.m.	Therapeutic procedures in rare diseases
11.20 a.m. - 1.00 p.m.	Social debate with public administration officials
2.00 p.m. - 4.00 p.m.	Dysmorphology session - syndromes with blefarofimosis and intellectual disability: clinical classification, etiology, symptomatology and diagnostics
4.20 p.m. - 6.00 p.m.	Dysmorphology session - discussion on unknown cases
8:00 p.m.	Formal Dinner
6 July 2014 (Sunday)	
8.00 a.m. - 1.00 p.m.	Diagnostic problems, unrecognized metabolic diseases
2.00 p.m. - 5.00 p.m.	Diagnostics and treatment of rare diseases in different countries, status presentation
5.00 p.m. - 6.00 p.m.	Medical consultations
6.00 p.m. - 7.00 p.m.	Dinner
7 July 2014 (Monday)	
7.00 a.m. - 8.00 a.m.	Breakfast
2.00 p.m. - 6.00 p.m.	Airport transfer
Parallel session - for patient organizations and members of the Federation of Rare Diseases Patients in Central and Eastern Europe	
4 July 2014 (Friday)	
10:30 a.m. - 1:30 p.m.	Rare diseases in Europe
2.30 p.m. - 6.00 p.m.	Legislation translated into practice of care for patients with rare diseases, the present and the future
7:00 p.m.	Barbecue (Dinner)
Parallel session - lectures for patients and carers	
5 July 2014 (Saturday)	
10.00 a.m. - 1.00 p.m.	Treatment, specialist medical care and rehabilitation
2.00 p.m. - 4.00 p.m.	Physiotherapy, psychotherapy and management of patients with rare diseases
8:00 p.m.	Formal Dinner

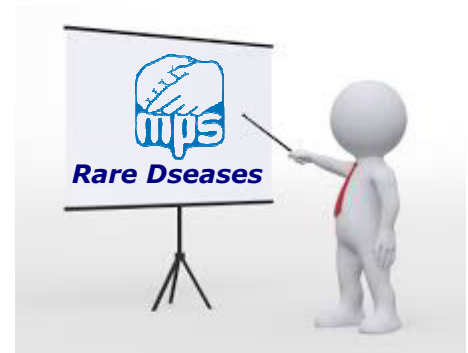
Co-organized by:

- 1 Federation of Rare Diseases Patients in Central and Eastern Europe
- 2 Association of Patients with Mucopolysaccharidosis and Rare Diseases, PL,
- 3 Ukrainian public organization “Association of Persons with Disabilities - Patients with MPS”
- 4 Belarusian Organization of Patients with MPS and Other Rare Genetic Disorders
- 5 Russian Association of Rare Diseases (^{RARD}) www.rare-diseases.ru
- 6 Union of Patients and Patient Organizations with Rare Diseases
- 7 EURORDIS, Rare Diseases Europe



Scientific Committee

- 1 Anna Tylki Szymańska, MD PhD (Warsaw)
- 2 Małgorzata Krajewska-Walasek, MD PhD (Warsaw)
- 3 Anna Latos-Bieleńska, MD PhD (Poznan)
- 4 Małgorzata Syczewska, MD PhD (Warsaw)
- 5 Aldona Dembińska-Kieć, MD PhD (Krakow)
- 6 Grzegorz Węgrzyn, PhD (Gdansk)
- 7 Agnieszka Ługowska, PhD (Warsaw)
- 8 Barbara Czartoryska, PhD (Warsaw)
- 9 Jolanta Wierzbą, MD (Gdansk)
- 10 Krumina Zita, MD PhD (Riga)
- 11 Natalia Pichkur, MD PhD (Kiev)
- 12 Ekaterina Zakharova, MD PhD (Moscow)
- 13 Jolanta Marucha, PhD (Warsaw)



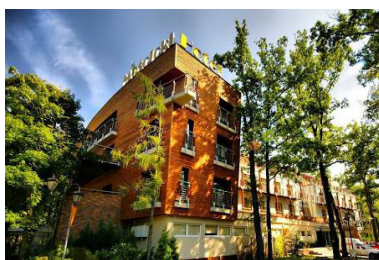
Organizing Committee

- 1 Teresa Matulka - President of the Board of the Society of Mucopolysaccharidosis and Rare Diseases
- 2 Małgorzata Doroba - Coordinator for International Relations, MPS and Rare Diseases
- 3 Justyna Matulka - Treasurer of the Society of Mucopolysaccharidosis and Rare Diseases
- 4 Anna Pruszyńska - Vice-President of the Society of Mucopolysaccharidosis and Rare Diseases
- 5 Aneta Trochimiuk - Member of the Board of the Society of MPS and Rare Diseases,

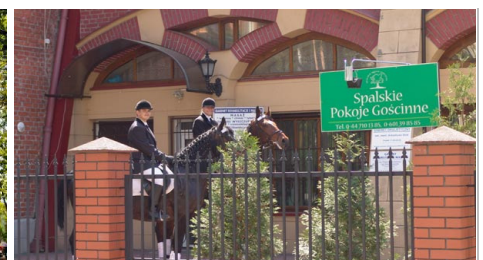
You will be provided with board and accommodation for the time of the Conference. The accommodation was booked in Hotel Mościcki**** Resort & Conference, Rezydencja Spalska and Spalskie Pokoje Gościnne - Carska Oranżeria. The quality of services together with natural beauty of the Spała Landscape Park will let you revive your spirits and optimism and restore your energy for further work.



Rezydencja Spalska
Spała, ul. Wojciechowskiego 15



Hotel Mościcki, Resort & Conference, Spała, ul. Nadpiliczna 2



Spalskie Pokoje Gościnne - Carska Oranżeria, Spała, ul. Wojciechowskiego 15

Pursuant to the Minister of Health Regulation of 6 October 2004 on the means of fulfilling the obligation of continuous medical education, participants to the Conference will be awarded educational points.

On behalf of the organizers of the Conference, you are now warmly invited to attend. You will be offered a friendly, family atmosphere, high quality lectures and relaxation amidst the natural wonders of the Spała Landscape Park.

Kindest regards,
President of the Society

Teresa Matulka

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